

# SPINAL COURIER

SPINAL CORD

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July 1996

# Wet and Wonderful!

"It was wet and rainy, but everyone had a good time." This comment summarizes the experience of the attendees of ASCC's seventh annual conference at the C.A. Vines Arkansas 4-H Center. Over 200 clients, family members, health care professionals, staff and speakers braved the early morning rain on Saturday, June 1st, and were rewarded with a great learning experience.

Sessions covered a variety of topics - something for everyone. The day began on an adventurous

note with speaker David Cornelsen taking everyone around the world with a discussion of his "1995 World Ride." This was followed by a panel presentation discussing their experiences in returning to work after their spinal cord injury. Twelve break-out sessions covered topics ranging from bowel management and nutrition to caregivers and wheelchair maintenance. At the end of the day everyone was treated to a session highlighting the 1996 Paralympic Games in Atlanta. Continued on page 6 - See "1996 ASCC

# **ASCIA Announces 1996 Scholarships**

Conference"

The Arkansas Spinal Cord Injury Association (ASCIA) has announced their 1996-97 scholarships. ASCIA President Bret Bridgers announced that four \$500 scholarships will be available for the 1996-97 school term. Applications are now available and must be submitted by August 19, 1996, for consideration.

In order to be eligible for the scholarship, the individual must:

- (1). have a spinal cord disability,
- (2). be officially accepted in a community college, university or vocational-technical training program for the Fall 1996 semester/quarter,
- (3). be enrolled for a minimum of 9 units for the Fall semester/ quarter,

(4). attend the Sept. 3, 1996, meeting of ASCIA (in Little Rock) in order to receive the scholarship.

Recipients may receive an ASCIA scholarship twice. ASCIA reserves the right to request additional financial information during the selection process.

"One of the primary goals of ASCIA is to assist Arkansans with spinal cord disabilities in achieving their goals and becoming self-sufficient," according to Scholarship Chairman Adrian Horton. Over the past three years ASCIA has granted \$7,500 in scholarships to 13 deserving individuals with spinal cord disabilities and looks forward to adding four more this year.

# Olympic Torch Rolls through Arkansas

On May 26th the Olympic Torch came through Little Rock on its way to Atlanta. Two community heroes selected to carry the Olympic Torch were Arkansans with spinal cord injuries. Sandy Turner, ASCC Commission member, and Gary Woodring, who works at Alliance HomeCare and is a member of the Rollin' Razorbacks, were chosen to be part of the Olympic Torch Run.



ASCC Commission Member Sandy Turner carrying the Olympic Torch on Scott Street, Little Rock, AR.

To receive a scholarship application, contact Scholarship Chairman Adrian Horton at 1-501-568-4286 or contact your ASCC Case Manager. Remember, the deadline for submitting applications is Monday, August 19, 1996.

#### SPINAL COURIER

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# **BUCKLE UP!**

# Time to Hit the Trail at Collier Homestead

Trails within Buffalo National River area provide access to some of the most beautiful scenery and historically valuable places in northwest Arkansas. Although much of the area is steep and remote, the National Park Service is striving to make its facilities accessible to all segments of the population. Recently a dedication ceremony of the Collier Homestead Trail was held in honor of National Trails Day, June 1, 1996. This packed gravel, wheelchair accessible trail follows an old roadbed 0.5 miles from the Collier Homestead parking area to a 1930's cabin and outbuildings.

An additional 0.5 mile section of the River View Trail, also wheelchair accessible, leads to a spectacular scenic river overlook. The trailhead of the Collier Homestead is at the Tyler Bend area of Buffalo National River. Tyler Bend is located three miles off Hwy. 65, thirty miles south of

### SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

#### **Hand Surgery for Quadriplegics**

Dear Editor:

I have just recently learned that University of Arkansas for Medical Sciences (UAMS) now has an Orthopedic Surgeon, Dr. Harris Gellman, with a special interest in improving the hand function of quadriplegics using tendon transfers. He has had extensive experience in this area and has written several medical articles on the subject. Four of his articles about quadriplegia are available from the ASCC Education and Resource Center (501-296-1792). Anyone who is interested in being evaluated by Dr. Gellman should call 501-296-1400 to request an appointment.

Shirley McCluer, M.D. ASCC Medical Director Little Rock. AR

### Wheelchair Quiz

- (1) A high powered pressure washer can be used to clean both manual and power wheelchairs?

  True or False
- (2) How many bearings does a manual wheelchair use? (a) 12 (b) 10 (c) 14
- (3) If your right rear wheel is low on air, which direction will it cause your chair to turn?

Right or Left

For Answers See Page 7

Harrison, AR and thirteen miles north of Marshall, AR. For more information on how you can travel this trail and enjoy the scenery, call the Tyler Bend Visitor Center at 501-349-2502, or park head-quarters at 501-741-5443, ext. 132.

#### **Any AT Lemons?**

Dear Editor:

Advocacy Services, Inc. (ASI) is conducting research to determine if users of assistive technology (AT) devices are experiencing difficulties with purchases/rentals of "lemon" devices. (For purposes of the research, a "lemon" device would be one which, due to manufacturer's defect, is not usable by the consumer for the intended purpose. Two or more breakdowns of the device in an initial twelve month period of time would also indicate a "lemon.") Anyone with a "lemon" story is requested to call me directly with the information. It will not be necessary for callers to use the ASI intake system to report any information.

To report difficulties with AT "lemons," please call me at (501) 296-1775 V/TDD or toll-free (800) 482-1174 V/TDD.

Dee Sharp Paralegal/Investigator Advocacy Services, Inc. Little Rock, AR

# Rollin' Razorback Going to the Paralympics

Tim Kazee, a member of the National Champion Rollin' Razorbacks will be representing the USA at the Paralympics in Atlanta. Tim is one of twelve members chosen to play on the Paralympic wheelchair basketball team.

Congratulations and Best of Luck, Tim!

# **HIGH PROFILE!**

# John Baker

This is the twelfth in a series of articles profiling the ASCC Case Managers.

"There is something valuable and, therefore, good in every one of life's experiences." This positive attitude has been the key to John Baker's success in providing services to many Pulaski County residents with spinal cord disabilities over the past three years. He energetically began his career with the Spinal Cord Commission in 1993 and hasn't had a chance to slow down yet.

After obtaining his Masters degree in Rehabilitation Counseling in 1992 from Memphis State University, John began his career as a Case Manager providing services to individuals with HIV/AIDS, working for Friend For Life in Memphis, TN. He also had direct experience working in crisis intervention and suicide prevention and providing counseling and advocacy to individuals with Multiple Sclerosis.

Fortunately for the Spinal Cord Commission, John's wife, Leslie, was accepted into the medical residency program at UAMS, thus precipitating their move to Little Rock. Since his arrival John has completed the requirements to become a Licensed Professional Counselor (LPC), made several presentations on behalf of the Commission, co-organized a successful support group, served on the Case Management Procedures Manual Committee and has become the "resident" audio/ visual expert for the annual ASCC conference.

Those of you who know John well, know his first love is music and he is often too modest regarding this talent. A recent write-up in the *Arkansas Democrat-Gazette* featured some of John's songs. After all, a man who owns seven guitars and various and sundry other musical instruments has to be "discovered" someday. Even



though John makes his own music wherever he goes, his genuine concern for people is still his best talent and he uses it wisely.

**FAMILY MEMBERS:** Leslie, my wife of nine years. My cats, Bonehead and her two children (who shall remain nameless!).

**PHRASE THAT BEST DESCRIBES ME:** Honest, friendly and caring.

**FAVORITE WAY(S) TO UNWIND:** Mountain biking, kayaking and playing guitar.

**HIDDEN TALENTS/HOBBIES:** I'm a songwriter. This talent (?) is a little too hidden, if you ask me!

**ACCOMPLISHMENT I'M MOST PROUD OF:** I started cycling two-and-a-half years ago, after a lifetime of being a couch slug. I'm now in the best shape - physically, mentally and spiritually - that I've ever been in.

**SOMETHING I'D CHANGE ABOUT MYSELF IF I COULD:** I'd be less critical of myself.

**LAST GOOD BOOK I'VE READ:** Actually it's two books, but they tell one story: *The Winds of War* and *War and Remembrance* by Herman Wouk.

**MY DREAM VACATION WOULD BE:** To wander around Europe for a month or two with my wife.

MOST IMPORTANT THING I'VE LEARNED AS A CASE MANAGER: There is something valuable and, therefore, good in every one of life's experiences. One must make a conscious decision to always seek out the valuable and the meaningful in even the worst of life's situations. If you look for the positive, you will find it.

# From the Director

It's been a year now since Superman joined the ranks of the spinal cord injured. The good news is Christopher Reeve survived (folks with injuries at his high level are at greatest risk the first year). He is back at home with his family, and seems, from the newspaper and television accounts, to be getting on with his life. He has the same worries as lots of folks with SCI: How can I get back to work? How do I get my transportation needs met? How can I modify my house so I can get around? And, what will I do when my insurance runs out?

Many of us wondered what impact he might have on the world of spinal cord injury. He certainly had the ability to be an apt spokesperson. I've been impressed with the role he has taken. From what I see, he's pursuing two major issues. First he has been a vocal proponent for spinal regeneration research and has spoken frequently, including to the U.S. Congress,

# With Thanks

The Arkansas Spinal Cord Commission accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission or send your donation to:

AR Spinal Cord Commission 1501 North University Suite 470 Little Rock, AR 72207

Donations this quarter from:

- The estate of John Honea
- Raj Allada

about the need for additional funding for this. But just as important, I think, to a lot of folks who live with SCI, he's become an advocate for healthcare reform - like removing the "caps" on insurance policies (even a million dollars doesn't go too far when you're a ventilatordependent quad) and allowing portability of coverage. The ideas aren't new: many advocates have been pushing these issues for several years at the state and national level, but, hey, who can argue with Superman? Here's hoping he has more luck than the rest of us have had!

Have a great summer - try to stay cool!

Cheryl L. Vines

### Congratulations Students!

Amanda Creamer of Harrison, was selected to the 1996 Arkansas Times Academic All Star Team. Amanda, 18, is a May graduate of Bergman High School and will attend Central Baptist College in Conway. She plans to study business administration and go into hotel restaurant management. Amanda's selection was based on both her academics (3.77 GPA) and her extensive extracurricular involvement

The Arkansas Governor's Commission on People with Disabilities has awarded scholarships to 15 persons to help further their college education. We wish to congratulate all of those students, and particularly ASCC clients, **Dana Harrison** and **Mike Wagner**, both of Little Rock.

# June Proclaimed Spinal Cord Injury Awareness Month



Governor Jim Guy Tucker proclaimed June 1996 as "Spinal Cord Injury Awareness" month in Arkansas at a proclamation ceremony in the Governor's Conference Room at the State Capitol on May 28, 1996. The Governor presented the proclamation to ASCC Commission Chair Grover Evans as Cheryl Vines, ASCC Executive Director, looked on. June, the first summer month, was selected as "Spinal Cord Injury Awareness" month nationally and in Arkansas since summer is the time of year when the largest number of traumatic spinal cord injuries occur.

#### **Changing Needs** Aging Bodies .

Written by The Rehabilitation Research and Training Center on Aging with Spinal Cord Injury, a joint project of Craig Hospital and the Department of Rehabilitation Medicine at the University of Colorado Health Sciences

You may have thought about the equipment changes - the power chair, the solid back, the van with the lift, the roll-in shower - but figured they were for those other people, not for you. Yet, you can't deny the increases in fatigue, in pain, in weight. And you can't deny the increased problems doing those things that used to be second nature. As we age, our bodies change, as do other things including energy level, situations, abilities, needs and helpers. It may be time for equipment changes....

Recent research in spinal cord injury and aging has been turning out some good news/bad news information. The good news? We're alive, relatively healthy and can count on a pretty normal life expectancy. The not-so-good news? Spinal cord injury isn't totally static as we had thought. Parts wear out, energy decreases, pain and needs go up. Does this mean that those young guys, the ones who can't imagine turning grey, are off the hook? In a word, no. Only some of this is due to aging.

Just as much of this not-so-good news has to do with the number of years post-injury as it does with getting old. Sometimes it's a question of high mileage and little or no maintenance. Common sense and planning together with some equipment and lifestyle changes - can go a long way in preserving health, energy, strength and independence, and in the process, quality of life. Often times, changes in equipment are the changes which do the most in allowing us to keep the function we have and maintain the quality of life we desire. How we regard these changes can be as important as the changes themselves.

Adaptive equipment can be viewed as those devices which narrow the gap between aspiration and ability, between what we want to do and what we are able to comfortably or safely do. Capitalizing on equipment can help to avoid pain, preserve energy and prevent future problems. Utilizing equipment can save large amounts of time and energy spent on such mundane things as dressing, bathing, getting from place to place,

or transferring in and out of a vehicle. While the thought of more equipment is often equated with loss of independence, incorporating new equipment into daily routines can preserve time and energy, helping to enhance as well as maintain both independence and quality of life.

#### Professional Observations, and Suggestions

Physical and occupational therapists find that they can make general predictions concerning their clients' changing equipment and environmental needs. These changing needs are usually in response to:

- lower strength and function,
- increased pain,
- decreased mobility,
- weight gain or loss,
- less activity,
- skin sores,
- posture problems,
- aging of the primary caregivers.

Another thing they find to predict equipment changes is fatigue and pain experienced by either the individual with spinal cord injury or the non-disabled spouse or caregiver. Fatigue is a significant predictor of several future problems, including depression, lower quality of life and in some survivors, the need for both more durable medical equipment and help from others. Fatigue can show up in ways other than just being tired. Lack of interest, irritability, crabbiness or giving up of enjoyable activities can indicate fatigue, and can also cover up the fear and depression that some find go along with aging bodies unable to do what they once did. Using new and different equipment is a logical way to maintain the constantly changing ability-energy balance.

Changes in equipment can include ultralight or power chairs and chair accessories, such as solid backs; transfer aides such as slide boards or transfer machines; bath equipment in the form of benches; and types of transportation, including car-top chair carriers to eliminate putting the chair in the car, or vans with lifts, which eliminate the need to transfer. Changing environmental needs of

their clients often lead therapists to focus on bathroom modifications such as extra grab bars or roll-in showers: lowered shelves and clothes poles in closets; and lowered counters in kitchens. Other accessibility and safety enhancing changes could include more gentle ramps, noncarpeted floors, door openers or speaker phones. The point is to be in charge of the environment rather than a prisoner of it.

Too often therapists encounter aging clients who are giving up things they enjoy - fishing, traveling, even working - because of pain, fatigue and other health issues. Yet these same clients continue to muscle their chairs into the car in order to drive, do difficult transfers and reject equipment or adaptations designed to enhance posture, protect skin or preserve range of motion, strength and energy. Reasons given have to do with personal appearance, perceived image and independence or infringement on schedules. Yet, their likely appearances, schedules and independence five, ten, fifteen years from now are hardly pretty pictures.

# Looking At the Donut and Not the

Ouality of life may be the prime consideration for changing equipment needs. Often it is simply a question of how we want to spend our time and what is truly important to us. Just as often, new equipment is a matter of preventative maintenance.

Quality of life and how we want to spend our time can certainly work at cross purposes to the independenceat-any-price approach. Is it truly more important to transfer to the bottom of the tub for a bath or shower, or is getting clean, which can be done using far less energy, as well as more quickly and safely from a bath bench, the real issue? Is it more important to expend energy doing car transfers, or is the energy better spent on the job and driving a van there? If wearing a corset provides the trunk stability necessary to make sit skiing fun rather than work, where's the concession or giving up? Continued on page 7 - See "Aging Bodies"

# 1996 ASCC Conference

Continued from page 1

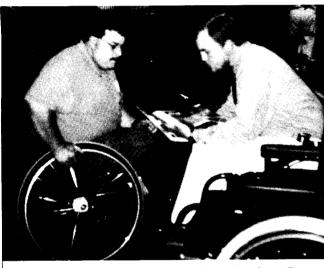
Of course, all the informative sessions were accompanied by plenty of socializing and eating. Next year's conference promises to be even bigger and better (and hopefully drier), so we hope to see all of you there!



David Cornelsen, Stephanie Wilchie-Bledsoe and Grover Evans take time out for the camera.



ASCC VISTA Volunteer Karen Schmidt and Ricky Lester of Hot Springs visit between sessions.



Carlos Turic gets some valuable information from Greg Watson of United Medical.



Ben Hollis, VAMC, is presented a \$100 gift certificate (donated by Harvest Foods) by ASCC staffer Patti Rogers. Ben promptly gave the prize to the White County SCI Support Group.

## New Videos in the ASCC Education & Resource Center on SCI

Sessions from the seventh annual conference, "Living with Spinal Cord Injuries in the '90's: Maximizing Your Options," are now available on video. These informative videotapes include:

- Opening Session, Keynote Address, "AXA World Ride '95: 'I Don't Believe in Can't'" (David Cornelsen, DSW), "Living with SCI and Working" (Panel Discussion)
- "Using Humor to Cope with a Disability" (Joyce Scott, ODHI)
- "Improving Your Skills in Discussing Sexual Issues"

- and "Sexual and Medical Options to Enhance Physical Intimacy" (Jane Brown, University of Alabama School of Medicine)
- "Caregivers" (Martha Henderson, ASCC)
- "Bowel Management and SCI" (Shirley McCluer, M.D., ASCC Medical Director)
- "Medicare Managed Care for SSDI" (Paul Davis, United Medical)
- "What You Need and How to Get It: Becoming Your

- Own Advocate" (John Baker, ASCC)
- "ADA/Civil Rights" (Charles Sabatier, Jr. and Steve Davis, Haskins, Sabatier & Miers)
- "Wheelchair Maintenance" (Lee Knuth, United Medical, and John Gould, ASCC VISTA Volunteer)
- "Nutrition Keys to Healthy Eating" (Grover Evans, Evans Consulting)

To check out a copy of any of these videotapes, contact Karen Schmidt in the Resource Center, **501-296-1792.** 

# Save Our Most Valuable Resource: Buckle Up Correctly!

Our children are our most valuable resource, therefore preventing childhood injury makes sense and saves lives. As always, ASCC works to promote educational information on how preventative measures do work. Statistics show that motor vehicle crashes are the leading cause of death and injury for young children. Over 3,200 children under the age of 16 died in motor vehicle crashes in 1994 and 350,000 were seriously injured. Sadly, a large percentage of these deaths and injuries could have been avoided if proper use of safety seats and restraints had been in use. Research on the effectiveness of their use has found they reduce fatal injury by 69 percent for infants less than one year old and by 47 percent for toddlers (one to four years old).

Child safety seats come in a variety of sizes, shapes and designs. They are meant to work in conjunction with the vehicle safety belt system. Child safety seats fall into three categories:

- (1) Infant seats are designed for babies from birth to approximately 20 lbs. and 26 inches in length. These are always installed rear-facing. If the vehicle is equipped with air bags, infant seats should always be in the rear seat of your vehicle.
- (2) Convertible seats convert from rear-facing to front-facing for toddlers weighing 20 to 40 pounds.
- (3) **Booster seats** (ideally used by children over 40 lbs. and 4 years old) are intended to be used as a transition to safety belts by older children who have outgrown the convertible seat.

Newer vehicles are frequently equipped with air bags which have appreciably reduced deaths in crashes. The National Highway Traffic Safety Administration (NHTSA) estimates that about 1,000



lives have been saved as a result of air bags since 1987.

However, it is a misconception that air bags eliminate the need for other types of protection such as seat belts and child safety seats. Several organizations including NHTSA and the National Transportation Safety Board have recommended (as reported in the May 31, 1996, issue of *Injury* Update), "Children less than 11 years of age should always wear seat-and-shoulder belts and ride in the back seat whenever possible. If they must ride in the front seat, the seat should be moved as far back from the air bag as possible." The purpose of this is to avoid air bag-induced injuries resulting from being too close to the air bag compartment, which can be the situation if the occupant is unbelted or improperly belted.

#### **Final Reminders:**

- Buckle up right low and tight.
- Buckle children correctly and securely in the appropriate child safety seat.
- Always follow manufacturer guidelines on installation.
- Be aware when it is time to change to a different seat as your child grows.
- Remember, children are not cargo and should never be allowed to ride in the cargo area of a truck, either with or without a canopy.
- Finally, USE SAFETY BELTS...IT'S THE LAW.

#### WHEELCHAIR QUIZ ANSWERS

(1). True (2). A (3). Right

# 1996 Spina Bifida Conference

The Spina Bifida Association of Arkansas (SBAA) will hold their 11th annual educational seminar on Saturday, October 12, 1996, in the Brandon Conference Center at Arkansas Childrens Hospital. Individuals with spina bifida, their families, heath care providers, educators and any interested individuals are welcome to attend. The Conference Program Committee, headed by SBAA President Jim Rucker and Vicky Rucker, are putting together a diverse program to include topics such as sexuality, transition, recreation and medical issues. Registration brochures should be available in early September. For additional information, contact the SBAA at 501-851-3351.

# **Aging Bodies**

Continued from page 5

We can only ask shoulders and arms to do the work of hips and legs for so long before the bill comes due. The bills can come in the form of blown shoulders, bad wrists, skin problems, chronic pain, excessive fatigue, disgruntled helpers. Adaptive equipment can be a way around the bills, a form of creative financing, if you will.

Each of us ages, and as we do our bodies change. Few of us can do at 40 or 50 what we did at 20. Similarly, the more years we spend postinjury, the more our bodies change. An important part of aging is using accumulated wisdom from past experience, ours and others', to avoid mistakes and future emotional and physical pain. Focusing on quality of life is truly what wisdom is about.

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# **Calendar of Upcoming Events**

#### Fall Fishing Derby

ASCC Fall Fishing Derby for the Russellville area will be held Saturday, Oct. 5, 1996, 10:00 am to 12:00 noon at Rest Haven Memorial Park Pond, Russellville, AR. Call the Russellville ASCC office at 501-890-5751 for more information.

#### SAILS PlayDay IV

Caddo Bend Swimming Area on Lake DeGray, outside of Arkadelphia, is the site of DeGray PlayDay IV, an upcoming event sponsored by SAILS (Spa Area **Independent Living Services**) of Hot Springs. Being held for the fourth year, DeGray PlayDay IV is an opportunity for people with disabilities and their families to enjoy swimming, boat riding, scuba diving or trying out certain types of adaptive skiing devices. DeGray Play-Day IV, Saturday, August 24, begins at 10:00 am with an afternoon cookout provided. Events last until dark. For more information contact SAILS at 501-624-7710 v/tdd.

#### ADSA Summer Activities

Several outdoors events sponsored by **Arkansas Disabled Sportsmen Association** (ADSA) this summer will include:

- Lower White River Float and Cat Fish Trip is scheduled for July/August.
- Trap and Skeet Shoot at the Remington Gun Club in Lonoke, AR is scheduled for August.
- Lake Ouachita, Crystal Springs Bass Fishing Trip is scheduled for September.
- Dove Hunt in Scott, AR is scheduled for September.

ADSA encourages those interested in any of the events to sign up early. For more information and to make reservations, call Joyce at **501-666-2523**.



#### Outdoor Education Extravaganza

DART (Disabled Accessing Recreation Together), a coalition to promote outdoor recreation for people with disabilities, invites Arkansans with disabilities to an Outdoor Education Extravaganza, Sept. 10-13, 1996, at Camp John Marks in Meridian, TX (85 miles south of Dallas). Camp John Marks is an accessible residential outdoor recreation center.

Activities will include educational experiences in several outdoor recreation pursuits, including Hunter Education on Sporting Rifles, an NRA Sporting Rifle Shoot, ATV Use and Awareness, Fly Rod Fishing Training and a Falconry Hunting Demonstration. For additional information about the Outdoor Education Extravaganza, contact Elaine Miller, DART Executive Director, at 205-879-0806 or write her at 1776 Independence Street, Ste. 350, Birmingham, AL 35216.

To have activities announced in the October '96 issue of Spinal Courier call the co-editors at 501-296-1784 by 9/20/96.

#### SPINAL COURIER

Arkansas Spinal Cord Commission 1501 North University, Suite 470 Little Rock, AR 72207

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